

# Autism Spectrum Disorder Task Force

MINUTES - September 22, 2014

Members present: Gerry Teevens, Connie Lillejord, Dr. Tom Carver, Nancy Ulrich Crotty, Kim Hruby, Teresa Larsen, Senator Joan Heckaman, Cathy Haarstad, Carolyn Fogarty, Tom Gaffney, John Porter

Others present: Trisha Page, Amanda Carlson, Vicki Peterson, Lorena Poppe, Lynn Dodge, Kristen Dvorak, Peggy Shireley

Agenda Items:

1. Welcome & Introductions
2. Review and approval of June 2014 minutes – Minutes approved with a change to refer to as an autism ‘database’ not a ‘registry’.
3. Task force membership update – tabled until next meeting
4. ND Autism Spectrum Disorder Advocacy Coalition (NDASDAC) report – update provided by Cathy Haarstad and Teresa Larsen
5. Autism Survey status – The survey has been widely distributed. This survey measures perception of services. There was discussion on handing out the survey at the conference. ND Center for Person with Disabilities is analyzing the surveys and within a month will issue the report. The report will be available with comparisons with the last survey done three years ago. At this time, there are 115 responders.
6. Legislative Human Services Interim Committee – The Committee requested information on the Autism Voucher Program. Trisha Page provided the testimony. The committee took no action.
7. SAND Grant & NDCPD Update – A no cost extension was asked for and is waiting for approval. The intent is to have teams trained across the state with the remaining funding. They request assistance with communicating with existing teams so they are aware of the continued funding. A western team is needed. Several ideas were issued to assist. Other ideas should be forwarded to Trisha or SAND staff. A recommendation that a link to the autism survey be sent to all registrants at the Autism conference. Trisha Page will research this possibility.
8. ND Department of Health - Autism Database – Testing is being done at this time. They are working on a specific reporting form and using TA from Sandra Howell, New Jersey as a model. Cody has created an expert panel that is meeting on October 23<sup>rd</sup>.
9. ND Department of Public Instruction updates - Overview of Autism Cares Handout. It must be done by August 18 of 2016 & delivered to legislators. The South Dakota study on distance education impact of ABA training was not funded. Prevalence rates of ASD – fourteen sites two slots that are open – joint SD and ND group.
10. ND Department of Public Instruction updates - Overview of Autism CARES Handout. It must be done by August 18 of 2016 & delivered to legislators. Guidelines completed and on website. Asked to send us a link. Blue bar. <http://www.dpi.state.nd.us/speced1/laws/laws/htmm>. CDCP can award grants under this act. Authorizing educational activities, Information must be culturally competent. A new report on young adults in transition must be issued – by August 8, 2016. Public comment asked as there were no parents involved in creating the ASD guidelines, if they met requirements. Response is that this is a good question for IDEA.
11. ND Department of Human Services Update
  - a. Waiver – Families are struggling with the application to Medicaid. Waiver service Update: There are 47 slots. New families continue to enroll. Currently serving transition families. There are 29 individuals

approved and several more in the next two weeks. By November 1<sup>st</sup> all screenings will be done and the waiver will be full. Only one person screened was not found eligible. There will be a wait list of about 14 people and last about two years unless someone leaves or is not found eligible. Families have a tremendous need for family support.

- b. Voucher – There have been 21 applications with some unusual requests. None of the voucher funds have been spent. People are asking for items or services, but not using the request form. The voucher is for ages 3 to 17.
- c. There are 2 autism briefing groups. One for parents and one for professionals.
- d. Training – Focus at this time is with the conference being held on October 20 – 22. There are over 40 presenters.
- e. Website – Updates are happening whenever possible.

12. Potential Autism-Related legislation.

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| f. Advocacy Coalition – Securing funding for Trisha's position, plus additional help for Trisha | n. Insurance mandate  |
| g. Adding more slots  | o. Continued funding for voucher & to increase to 300% of poverty |
| h. Increasing the age to 21   | p. Increase funding dollars for voucher program                   |
| i. Increase funding for support to parents  | q. Having adequate funding for service providers                  |
| j. Continued funding for conference   | r. Ask for administrative assist and parent support               |
| k. Funding for a database   | s. Ask for money for training videos                              |
| l. Funding for SAND Grant   |   |
| m. Training for first responders and educators  |   |

13. Review & Continued work on Autism Plan

- 14. Other items: Family Voices will continue monthly calls with families of children with ASD. There is an RFP with required membership, scope of work and duties and reimbursement rate with additional members as needed. The state will purchase the ADOS for the teams. Good information to pass on.
- 15. John Porter –Special Education– Legislative issues – multiple agencies working together can ensure funding easier. The study council group doesn't represent education – open to bring names forward – Leona and Jessie Krieger are willing. Definitely see that more gets done with a united front. From the task force point of things hope we have separate bills. We are all looking for one bill to stand behind.
- 16. Key piece is cost of speech OT PT can't find and retain. Lot of out of people state are getting the SLP slots and then moving home. Many directors had not keyed in on the voucher. Needs to come from a family and school can help them complete.
- 17. Insurance mandates – few kicked back to school – school didn't have anything to do with it.
- 18. Senator Heckaman – Funding for Federation of Families and Family Voices to join funding for non-profits as grants deplete. She will be meeting with them.
- 19. Advocacy group can meet one more time. Training videos as a recommendation. One bill is enough.
- 20. Dr. Carver – trying to get more children identified through multi-disciplinary clinics. Minot, Fargo, Jamestown – can't get paid for it. Need to be able to be reimbursed for it. Best practice is arena style assessments. Sanford is using interdisciplinary approach and they are able to bill.
- 21. Date of next meeting – December 10, 2014, 10:30 – 3:30